NACC

NACC UNIFORM DATA SET COVID Impact Forms

Version 2.0, July 2022

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Form F1 COVID-19 Technology Accessibility Survey Form F2 COVID-19 Impact Survey: Participant, v2 Form F3 COVID-19 Impact Survey: Co-Participant, v2



Forms F2 and F3: COVID Impact Survey

Instructions for the Center

This updated COVID-19 survey is an optional form to be filled out by either the participant (if CDR[®] Dementia Staging Instrument score = 0 or 0.5) or co-participant/caregiver on behalf of the research participant (if CDR[®] > 0.5); alternatively, it may be administered by study personnel. Participants may decline to answer questions. If Centers want to obtain information on additional issues related to COVID-19, they may do so locally, but any additional material will not be collected for NACC.

This form serves as an update to the original COVID-19 impact Survey released in summer 2020, and reflects on several important updates since that time, including vaccinations, repeat infections, evolving understanding of the long-term impacts of COVID-19 particularly on cognitive function, and broader psychosocial stressors which occurred in the same timeline as the initial and subsequent waves of the pandemic. In addition, it is recognized that many of these aspects of the COVID-19 pandemic may have been experienced differently person to person as well as community to community. The survey is intended to capture a summative experience since the onset of the pandemic, may be used either during initial or follow-up visits, and is potentially adaptable to delivery between those times.

Attached to this participant form is a supplemental form for co-participants/caregivers of participants with a CDR[®] > 0.5. This survey is also optional for Centers. Again, if Centers want to obtain information on additional caregiver issues related to COVID-19, they may do so locally, but this additional material will not be collected for NACC.

These surveys may be administered by Centers in conjunction with, or unique and separate from, annual in-person or telephone UDS visits. The timing and option to participate in collection of this important data is entirely up to the individual Centers that are part of the NIA ADRC Program. Each Center should consider administering these surveys to as many participants as possible through either mail, telephone, video, and/or in-person contacts. Centers will need to provide information to participants about local vaccination availability for unvaccinated participants that request information.

We have tried to capture important scientific information regarding COVID-19 exposure, medical consequences, and impact on social situations; on cognitive, psychiatric, and behavioral issues; and on caregiver burden and related issues. This information may prove to be extremely useful in our understanding of the impact of such a pandemic on the aging population today and the future.

Form F2: COVID Impact Survey—Participant

ADRC name:	Partici	pant ID:	Form date:	/	/
Examiner's In	itials:				
For Clinic	al Staff				
	Is the participant's $CDR^{\circ} > 0.5?$			□ 0 No □ 1 Yes	
	Who will be filling in the F2 Partici	pant form?		□1 Parti □2 Co-p □3 Clini	articipant
	How are you administering the F2	form?			erson electronic erson printed form I
				cont	inue to participant form

NATIONAL ALZHEIMER'S COORDINATING CENTER | (206) 543-8637 | fax: (206) 616-5927 | naccmail@uw.edu | naccdata.orgCOVID Impact Survey, Participant, July 2022Page 1 of 12



Form F2: COVID Impact Survey—Participant

ADRC name:	Part	ticipant ID:	Form date:	/ /	
Examiner's Ini	itials:				
administe challenge affects me alright to	ered to you by research study st es for us all, and we would like to emory and health. As a research	<u>onal form</u> we would like you to aff). We are asking these questi o learn about your experience. N n participant, you may decline to ny of the questions as you feel o g COVID-19.	ons because COVID We also would like t o answer any of the	-19 has presented r o learn how COVID se questions, and it	nultiple -19 : is
1.	and/or were diagnosed with CC 0 No (continue) 1 Yes, based on a positive t 		JESTION 4)	P TO QUESTION 4)	
2.	think you had COVID-19 (novel	:, have you experienced new or wo coronavirus) such as fever, cough, o aking with chills, muscle pain, heac ouse, or bluish lips or face? 8 Decline to an 9 Unsure/unkn	difficulty breathing, p lache, sore throat, ne iswer	persistent pain or pre	ssure
3.		but unable) (SKIP TO QUESTION 10 ant to get tested) (SKIP TO QUESTIO KIP TO QUESTION 10) an once (SKIP TO QUESTION 10) O QUESTION 10)			
4.	If 100% is feeling perfectly nor what percent of normal do you % (IF QUESTION 4 = 100%, SKIP TO QU 4a. If not 100%, why are you no	UESTION 5)	ID-19 symptoms),		
					continued

ADRC	name:
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Examiner's Ini	itials:
5.	Over the past month, how often did symptoms from past or current COVID-19 infection(s) affect your daily life? 1 Never 2 Seldom (1-2 days per week) 3 Sometimes (3-4 days per week) 4 Often (5-6 days per week) 5 Every day 8 Decline to answer
6.	How many times have you been diagnosed with COVID-19 (distinct episodes of infection)? 1 Once 2 Twice 3 Three or more times 9 Unsure/unknown
	6a. When did your first COVID-19 infection begin <i>(month/year)?</i> (88/8888 = Decline to answer, 99/9999 = Unknown) / /
	6b. What was the duration of symptoms from your first COVID-19 infection? 0 Never had symptoms 4 > 4 weeks 1 < 1 week 5 Not yet recovered (symptoms persist to the present) 2 1-2 weeks 8 Decline to answer 3 2-4 weeks 9
	(IF QUESTION 6 = ONCE (ONLY DIAGNOSED ONCE), SKIP TO QUESTION 7) 6c. When did your most recent COVID-19 infection begin (month/year)? (88/8888 = Decline to answer, 99/9999 = Unknown) /
	6d. What was the duration of symptoms from your most recent COVID-19 infection? 0 Never had symptoms 4 > 4 weeks 1 < 1 week 5 Not yet recovered (symptoms persist to the present) 2 1-2 weeks 8 Decline to answer 3 2-4 weeks
7.	During any of your COVID-19 infections, did you lose the ability to smell or taste, experience lower ability to determine smells or tastes, or experience episodes of unprovoked, unfamiliar, or strange smells or tastes? 0 No (SKIP TO QUESTION 8) 8 Decline to answer (SKIP TO QUESTION 8) 1 Yes (CONTINUE) 9 Unsure/unknown (SKIP TO QUESTION 8)

ADRC name: Examiner's In		nt ID: / / /	/
	7a. When did you first experience (88/8888 = Decline to answer, 99/9999 /	changes in smell or taste <i>(month/year)?</i> = Unknown)	
	7b. How long did it take to recove	r smell and taste fully?	
	□ 1 < 1 week □ 2 1-2 weeks □ 3 2-4 weeks	 4 > 4 weeks 5 Not yet recovered (symptoms persist to the president of the	sent)
8.	During any of your COVID-19 infec or concentration (<i>e.g., brain fog</i>)?	tions, did you experience new problems with thinking, remer	mbering,
	□ 0 No (skip to question 9) □ 1 Yes (continue)	 B Decline to answer (SKIP TO QUESTION 9) Unsure/unknown (SKIP TO QUESTION 9) 	

8a. When did you first experience changes in thinking, remembering, or concentration (*month/year*)? (88/8888 = Decline to answer, 99/9999 = Unknown)

8b. How long did it take to recover changes in thinking, remembering, or concentration?

□ 1 < 1 week □ 2 1-2 weeks □ 3 2-4 weeks		 4 > 4 weeks 5 Not yet recovered (symptoms persist to the present) 8 Decline to answer
211		

9. Did you ever seek medical care for COVID-19?

_ ___ / ___ __ ___

0 No (SKIP TO QUESTION 10)	8 Decline to answer (SKIP TO QUESTION 10)
1 Yes (continue)	9 Unsure/unknown (SKIP TO QUESTION 10)

9a. Did you receive any type of outpatient treatment for your COVID-19 infection such as monoclonal antibody treatment, oral antiviral, subcutaneous injection of antiviral, or other treatment?

0 No (SKIP TO QUESTION 9b)	
1 Yes (CONTINUE TO QUESTION 9a1)	

/ _

 8
 Decline to answer (SKIP TO QUESTION 9b)

 9
 Unsure/unknown (SKIP TO QUESTION 9b)

9a1. When did you receive this outpatient treatment *(month/year)*? (88/8888 = Decline to answer, 99/9999 = Unknown)

 ADRC name:

 Participant ID:

 Form date:

 / ______

Examiner's Ini	tials:	
	 9b. What was the highest level of medical care you received for COVID-19? 1 Phone consultation or virtual care visit (SKIP TO QUESTION 10) 2 In-person physician or urgent care visit (SKIP TO QUESTION 10) 3 Emergency department (SKIP TO QUESTION 10) 4 Hospitalized but not the intensive care unit (ICU) (CONTINUE) 5 Hospitalized, including a stay in the ICU and/or ventilator support (breathing tube in your throat) (CONTINUE) 8 Decline to answer (SKIP TO QUESTION 10) 9 Unsure/unknown (SKIP TO QUESTION 10) 	
	 9c. How many times have you been admitted to the hospital for COVID-19? 1 Once (CONTINUE) 2 Twice (CONTINUE) 3 Three or more times (CONTINUE) 9 Unsure/unknown (SKIP TO QUESTION 10) 	
	When were you admitted to the hospital for COVID-19? If you were hospitalized more than once, please report the 3 most recent hospitalizations.	
	9c1. Month/year of most recent hospitalization: (88/8888 = Decline to answer, 99/9999 = Unknown) / /	
	9c2. How many days were you hospitalized? (888 = Decline to answer, 999 = Unknown)	
	(IF ONLY HOSPITALIZED ONCE, SKIP TO QUESTION 10) 9c3. Month/year of next most recent hospitalization: (88/8888 = Decline to answer, 99/9999 = Unknown) //	
	9c4. How many days were you hospitalized? (888 = Decline to answer, 999 = Unknown)	
	(IF ONLY HOSPITALIZED TWICE, SKIP TO QUESTION 10) 9c5. Month/year of next most recent hospitalization: (88/8888 = Decline to answer, 99/9999 = Unknown) //	
	9c6. How many days were you hospitalized? (888 = Decline to answer, 999 = Unknown)	
		continued

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_ Participant ID: _____ Form date: ____ / ___ / ___ / ___ __ __

Examiner's Ini	tials:				
10.	Have you received at least one vaccination against CO 1 No (CONTINUE) 1 Yes (SKIP TO QUESTION 10b) 8 Decline to answer (SKIP TO QUESTION 11) 9 Unsure/unknown (SKIP TO QUESTION 11)	/ID-19?			
	10a. Why have you not received a COVID-19 vaccination?				
	 Wanted to but unable (SKIP TO QUESTION 11) Did not want to get vaccinated (SKIP TO QUESTION 11) Allergy (SKIP TO QUESTION 11) Medical contraindication 	 5 Other (SPECIFY & SKIP TO OUESTION 11): B Decline to answer (SKIP TO QUESTION 11) 9 Unsure/unknown (SKIP TO QUESTION 11) 			
	(SPECIFY & SKIP TO OUESTION 11):				
	10b. How many COVID-19 vaccine doses have you received?				
	 1 One: Partial vaccination (one dose of two-dose series) 2 One: One-dose series, e.g., Janssen (Johnson & Johnson) without booster 3 Two: Two-dose series without booster 4 Two: One-dose series with one booster 5 Three: Two-dose series with one booster 6 Three +: One-dose series with more than one booster 7 Four +: Two-dose series with more than one booster 8 Decline to answer (SKIP TO QUESTION 11) 9 Unsure/unknown (SKIP TO QUESTION 11) 				
	10c1. When did you receive your first COVID-19 vaccination (month/year): (88/8888 = Decline to answer, 99/9999 = Unknown) / /				
	10c2. Which COVID-19 vaccine did you first receiv	re?			
	1 Pfizer 8 Decline to answer 2 Moderna 9 Unsure/unknown 3 Janssen (Johnson & Johnson) 9 Unsure/unknown 4 Other (SPECIFY): 1 1				
	10c3. Did you experience any symptoms within 5 days of your first COVID-19 vaccination?				
	□ 0 No (skip to question 10d1) □ 1 Yes (continue)	8 Decline to answer (SKIP TO QUESTION 10d1) 9 Unsure/unknown (SKIP TO QUESTION 10d1)			

10c4. Which of the following symptoms did you experience after your first vaccine? (SELECT ALL THAT APPLY)
1 Sore arm
10c4a1. Number of days sore arm lasted: (999 = Uncertain, 777 = Continued through now)
□ 2 Flu-like feelings (fever, chills, tiredness, or "malaise")
10c4b1. Number of days flu-like feelings lasted: (999 = Uncertain, 777 = Continued through now)
□ 3 New problems with memory, thinking, or concentration
10c4c1. Number of days new problems with memory, thinking, or concentration lasted: (999 = Uncertain, 777 = Continued through now)
□ 8 Decline to answer □ 9 Unsure/unknown
10d1. When did you receive your second COVID-19 vaccination <i>(month/year)?</i> (If Question 10b = 1 or 2 (one dose, no booster), skip to Question 11. If Question 10b = 4 or 6 (one dose with booster), skip to Question 10e1. If decline to answer, enter 88/8888. If date unknown, enter 99/9999.) / /
10d2. Which COVID-19 vaccine did you receive?
1 Pfizer 8 Decline to answer 2 Moderna 9 Unsure/unknown 3 Other (SPECIFY): 1 1
10d2 Did you experience any symptoms within 5 days of your second COVID 10 vassination?
10d3. Did you experience any symptoms within 5 days of your second COVID-19 vaccination?
0 No (SKIP TO QUESTION 10e1) 18 Decline to answer (SKIP TO QUESTION 10e1) 1 Yes (CONTINUE) 9 Unsure/unknown (SKIP TO QUESTION 10e1)
10d4. Which of the following symptoms did you experience after your second vaccine? (SELECT ALL THAT APPLY)
1 Sore arm
10d4a1. Number of days sore arm lasted: (999 = Uncertain, 777 = Continued through now)
2 Flu-like feelings (fever, chills, tiredness, or "malaise")
10d4b1. Number of days flu-like feelings lasted:
(999 = Uncertain, 777 = Continued through now)
continued

name:

Examiner's Initials:

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_____ Participant ID: _____ Form date: ____ / ____ / ____ / ____ __

□ 3 New problems with memor	y, thinking, or concentration	
10d4c1. Number of days r (999 = Uncertain, 777 = Contin	new problems with memory, thinking, or concentratio inued through now)	on lasted:
□ 8 Decline to answer	□9 Unsure/unknown	
	st COVID-19 booster vaccination (month/year)? hout booster), skip to Question 11. If decline to answer, enter	88/8888.
10e2. Which COVID-19 vaccine d	did you receive?	
☐ 1 Pfizer ☐ 2 Moderna ☐ 3 Other (specify):	☐ 8 Decline to answer ☐ 9 Unsure/unknown	
10e3. Did you experience any sy	/mptoms within 5 days of your first COVID-19 booster va	accination?
□ 0 No (skip to question 10f) □ 1 Yes (continue)		
10e4. Which of the following syr (SELECT ALL THAT APPLY)	mptoms did you experience after your first booster vac	cination?
\Box_1 Sore arm		
10e4a1. Number of days s (999 = Uncertain, 777 = Conti 		
2 Flu-like feelings (fever, chills,	, tiredness, or "malaise")	
10e4b1. Number of days 1 (999 = Uncertain, 777 = Contin		
 3 New problems with memor	ry, thinking, or concentration	
10e4c1. Number of days n (999 = Uncertain, 777 = Contin 	new problems with memory, thinking, or concentration inued through now)	n lasted:

ADRC name:	Participant ID:	Form date: / / /
Examiner's Ini	itials:	
	10f. When was your most recent COVID-19 vac (If Question 10b = 4 or 5 (only one booster received), If date unknown, enter 99/9999.) /	cination/booster (<i>month/year</i>)? skip to Question 11. If decline to answer, enter 88/8888.
11.	Do you need help in setting up a COVID vaccin \Box_0 No \Box_1 Yes (Center will provide information)	\square_8 Decline to answer
12.	□ 2 A little worried	will get COVID-19 <i>(or, if previously infected,</i> 4 Very worried 5 Extremely worried 8 Decline to answer
13.	2 A little disruptive	-19 pandemic been to your everyday life?]4 Very disruptive]5 Extremely disruptive]8 Decline to answer
14.	On a scale of 1-6 (with 1 being "I can shake off str your ability to handle stress? 1 "I can shake off stress" 2 3 4 5 6 "Stress eats away at me" 8 Decline to answer	ress" and 6 being "Stress eats away at me") how would you rate
15.	In the past year, on a scale of 1-6 with 1 being " the amount of stress in your life <i>(at home and a</i> 1 "No stress" 2 3 4 5 6 "Extreme stress" 8 Decline to answer	no stress" and 6 being "extreme stress" how would you rate t work)?
16.	On a scale of 1-5, how much has COVID-19 char if it requires in-person visits to the research clir 1 Not at all 4 Very m 2 A little 5 Extrem 3 Somewhat 8 Decline	uch ely
		continued



Form F3: COVID Impact Survey—Co-Participant

ADRC name:	Participant ID:	Form date:	/ /	

Examiner's Initials:

Instructions for the Center

The following COVID-19 survey is an <u>optional form</u> we would like you to fill out *(alternatively, the survey may be administered to you by research study staff)*. We are asking these questions because COVID-19 has presented very new challenges for us all, and we would like to learn about your experience. We also would like to learn how COVID-19 may have affected your well-being and your ability to support the research participant as their co-participant/caregiver. You may decline to answer any of these questions, and it is alright to do so, but please answer as many of the questions as you feel comfortable with. Your research Center may also have additional questions regarding COVID-19.

	n family and friends have you felt due to the COVID-19 pandemic?
$\Box_1 = \text{Not at all isolated}$ $\Box_2 = \text{A little isolated}$ $\Box_3 = \text{Somewhat isolated}$	$\Box_4 \ 4 = Very \text{ isolated}$ $\Box_5 \ 5 = Extremely \text{ isolated}$ $\Box_8 \ 8 = Decline \text{ to answer}$
On a scale of 1-5, how disruptive has the COV \square 1 = Not at all disruptive \square 2 = A little disruptive \square 3 3 = Somewhat disruptive	 /ID-19 pandemic been to your everyday life? 4 4 = Very disruptive 5 5 = Extremely disruptive 8 8 = Decline to answer
	 1 1 = Not at all isolated 2 2 = A little isolated 3 3 = Somewhat isolated On a scale of 1-5, how disruptive has the COV 1 1 = Not at all disruptive 2 2 = A little disruptive 3 3 = Somewhat disruptive On a scale of 1-5, since the start of the COVID that you were unable to control the important is a scale of 1-5, since the start of the COVID that you were unable to control the important is 3 3 = Sometimes On a scale of 1-6 (<i>with 1 being "I can shake of</i> how would you rate your ability to handle set 1 "I can shake off stress" 1 "I can shake off stress" 6 "Stress eats away at me"

ADRC	name:
ADRC	name:

Participa	nt ID:

Examiner's Initials:

5.	In the past year, on a scale of 1-6 with 1 being "no stress" and 6 being "exhow would you rate the amount of stress in your life <i>(at home and at world)</i> 1 "No stress" 2 3 4 5 6 "Extreme stress" 8 Decline to answer		s"	
6.	Regarding your feelings of connectedness with friends and family durin did you feel or have you felt 1 Less connected 2 About the same level of connection 3 More connected 8 Decline to answer	g the COVID	-19 pandem	ic,
7.	Has the COVID-19 pandemic affected your ability to provide care for the 1 It is easier to provide care 2 I am managing the same as always 3 It is somewhat more difficult to provide care 4 It is extremely difficult to provide care 8 Decline to answer	research pa	rticipant?	
		No	Yes	Decline to Answer
8.	What kind of care assistance, if any, has become harder to access?			
	8a. Respite by family or friends	0	□ 1	8
	8b. Paid respite by care agencies	□ o	1	8
	8c. Day activity programs	□ o	□ 1	8
	8d. Overnight or extended-stay respite care	0	□ 1	8
	8e. Ability to find skilled residential facility placement	0	□ 1	8
	8f. Medical care including physician appointments	0	1	8
	8g. Other (SPECIFY):	□ o	□ 1	8

ADRC name:	Participant ID: Form date: / / / /
Examiner's Ini	tials:
9.	On a scale of 1-5, how much has the COVID-19 pandemic changed your willingness to allow or encourage your care partner's participation in clinical research if it requires in-person visits to the research clinic? $\Box_1 \ 1 = \text{Not at all}$ $\Box_4 \ 4 = \text{Very much}$ $\Box_2 \ 2 = \text{A little}$ $\Box_5 \ 5 = \text{Extremely}$ $\Box_3 \ 3 = \text{Somewhat}$ $\Box_8 \ 8 = \text{Decline to answer}$
10.	On a scale of 1-5, how much has the COVID-19 pandemic changed your own personal willingness to participate in clinical research, irrespective of whether in-person or telephone/remote visits are used? 1 1 = Not at all 4 4 = Very much 2 2 = A little 5 5 = Extremely 3 3 = Somewhat 8 8 = Decline to answer
11.	Do you have specific care needs that are not addressed above? Please list any care needs (both yours and the research participant's) that are not being met because of the COVID-19 pandemic: